

Politicians Say They Aren't Cutting Benefits
to People With AIDS. But They Are.

The Big Lie

REPUBLICAN welfare rhetoric never sounds phonier than when it encounters AIDS. It's not "tough love" to reduce medical benefits for people with a life-threatening illness, or to cut back on their money for food or shelter. It's just mean.

Maybe that explains why many politicians insist they are sparing people with HIV from their budget cuts. Take Lieutenant Governor Betsy McCaughey, architect of the Pataki administration's Medicaid cutbacks. "We did not cut any programs designed to meet the needs of people living with HIV," she maintains. In the narrowest sense, McCaughey is right: Special programs for people with AIDS were left intact. But indigent people with the disease depend on Medicaid's general programs, not just the few earmarked for HIV, and the state is pruning the whole Medicaid tree.

The same holds for welfare services. People with AIDS depend on them, but Pataki, Giuliani, and the Republican Congress are hacking away at those programs, too.

To maintain their health, poor people with AIDS depend on a continuum of care that encompasses housing, nutrition, transportation, medical and home care, counseling, cash assistance, legal advocacy, and treatment for addiction. "If you pull out any one of those strings," cautions Keith Cylar, co-executive director of Housing Works, a nonprofit agency that provides shelter to people with HIV, "you begin to unravel the whole continuum."

The proposed cuts are often so complex and arcane that it's difficult to assess their impact on people with AIDS. One example: the Pataki Medicaid bill limiting reimbursement of something called Alternate Level of Care (ALOC) to 15 days per year.



Marlene and her daughter Margaretha are HIV-positive: "The baby comes first."

ALOC is the care hospitals give when a patient no longer needs acute treatment and could switch to a nursing home or home care. But the governor's bill reduces these services too, so advocates fear that patients might have nowhere to go after their 15-day limit. At that point, financially strapped hospitals might dump them. People with AIDS are especially vulnerable to such penny-pinching, because they are often hospitalized several times a year, making them more likely to exhaust their annual ALOC allotment.

Most AIDS advocates support welfare reform. They note that the current system forces sick people to spend down and become poor in order to qualify for aid, and that it forces recipients to wander through a bureaucratic labyrinth. But the current cuts do not reform; they simply slash. The result will not be a more effective welfare system, but one that hurts the least among us—such as people with AIDS.

The following profiles demonstrate how people with AIDS rely on various programs slated to be pared. Most of these faces are black or Latino, and most are women. They are the people most likely to need public assistance. Here, they describe the impact the proposed cuts would have on their lives.

BY MARK SCHOOF S
PHOTOGRAPHS BY JAMES HAMILTON

MARLENE AND MARGARETHA DIAZ

Watching her daughter rummage through a heap of toys, Marlene Diaz says, "I'm a firm believer in keeping her life as normal as possible." That's a challenge, since mother and child are both infected with HIV. The virus has caused two-year-old Margaretha to suffer from thrush, diarrhea, and a mysterious infection that forced her into the hospital. Especially for them, a "normal" life requires money.

Marlene bristles that welfare considers some of her expenses to be "frills," such as homeopathic therapies, child care for her daughter, and side-by-side mausoleum berths located "off the No. 1 train, so whoever wants to go visit doesn't have to count on someone schlepping them in a car." But no one would consider food a frill, even though Margaretha has turned out to be a finicky eater.

HIV has impaired Margaretha's ability to absorb nutrients. She needs special baby formula that is high in nutrients and easy to digest. Luckily, she receives about \$150 worth of exactly that kind of formula, as well as juices and other healthy foods, through the federal government's Special Supplemental Nutrition Program for Women, Infants, and Children—or WIC. Created to reduce the incidence of low birth weight, the program has lowered infant mortality and child anemia, saving taxpayers future Medicaid costs. Its benefit to poor children with AIDS, many of whom suffer from malabsorption similar to Margaretha's, is a fortunate coincidence.

But WIC is being cut. A House committee has recommended that money for the program be given to states in a block grant, a lump of money—but less than before—that states can spend with virtually no restrictions. Gone will be nutrition standards, and even the requirement that states use competitive bidding to purchase infant formula. That requirement saved more than \$1 billion last year, allowing the program to serve an additional 1.5 million mothers and children at no additional cost to taxpayers.

House Republicans have also targeted food stamps. They aim to shrink its budget, and to detach benefit levels from inflation, which means that the stamps would gradually buy less and less.

Every month, Marlene juggles her bills, paying some in full while leaving others till the next cycle. Last month, she didn't have enough cash to buy the vitamin supplements she needs. If WIC is cut, Marlene will have to further sacrifice her own needs. "The baby comes first, and that's

not because I'm Catholic and love being a martyr," she says wryly. "It's because after seeing her in the hospital for a week, I just have to do anything to help her. I just do."

KENNETH WILLIAMS

Kenneth Williams's problem is that he's not sick enough. He's infected with HIV, and suffers from syphilis, recurrent diarrhea, shingles, cold sweats, and a skin disorder so rare it has baffled his doctors. But his T cells float at a lofty 585, well above the official definition of AIDS. That might be why SSI and SSD, the federal disability programs, have rejected Williams three times since he applied a year and a half ago. Or the reason might be that Williams, like many poor people, has medical records scattered among various clinics and hospitals. That makes it hard for

a month and a New York State program called Home Relief. Designed to catch those who fall through the cracks of other welfare programs, Home Relief provides cash—\$352 a month in Williams's case—to pay for rent and other basic living expenses.

The Pataki administration has proposed restricting Home Relief—which is currently available indefinitely—to three months a year for anyone deemed "employable." Congressional Republicans have proposed the same for food stamps. In addition, Pataki's Home Relief proposal would slash assistance to employable recipients by 25 per cent and to the unemployable by 15 per cent. Pataki's budget office declines to label the latter a reduction. Instead, a spokesperson insists it is a "repeal of a 1990 increase."

The fate of Williams—and the many people like him—hinges on the definition of "employable." Two state officials have

could be forced to find work or be cut off these lifesaving programs altogether.

Most people with AIDS want to work, and do so as long as they can. But, aside from feeling ill much of the time, Williams doubts anyone would hire him or keep him for long. "Employers don't want to hear you're sick," says Williams, who served in the army for four years and then held clerical and warehouse jobs until 1992. "How can I tell them, 'Look, I'm HIV, I have to go to the doctor'? How do I tell them, 'Today I don't feel good'? How do I tell them that when I just found a job?"

What would happen if he lost his Home Relief or food stamps? "Forget it," he says. "You might as well throw the dirt on me."

JOHN DEFAZIO

On his eighth birthday, John DeFazio's dad gave him his first glass of wine. By 12, he was smoking marijuana "on the corner, with the wrong group of people." At 21, he tried cocaine for the first time, and that same year his brother "gave me my wings, as they call it, with intravenous drugs."

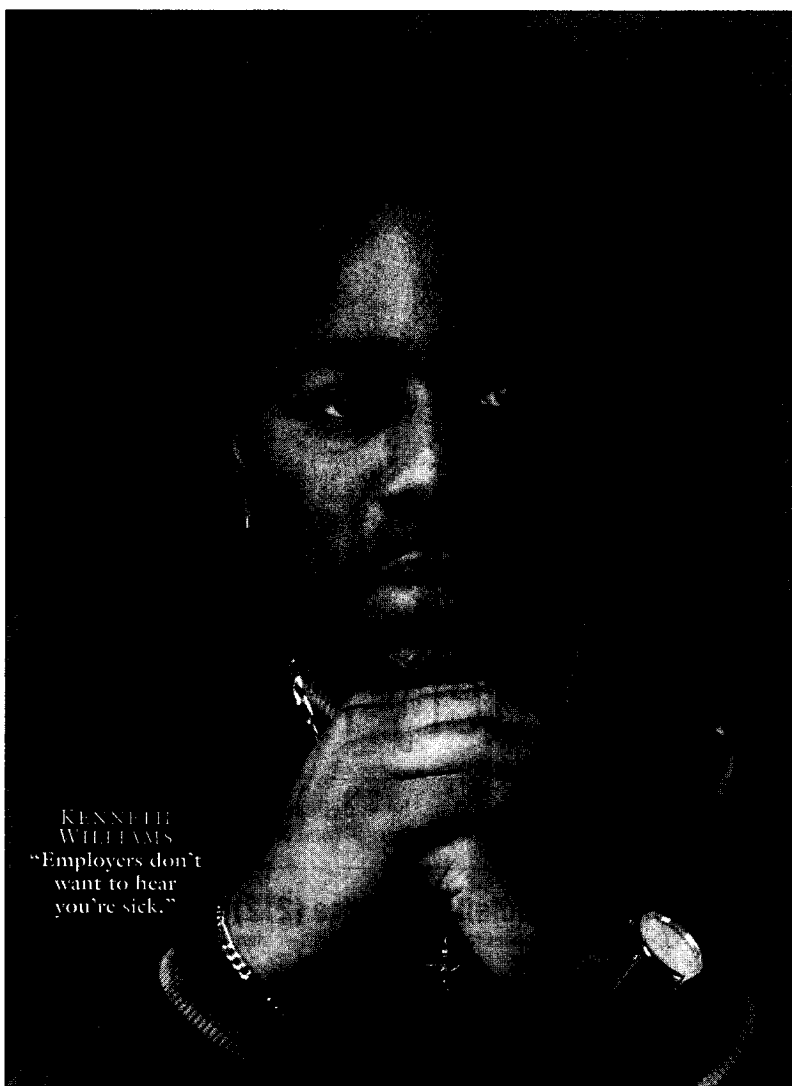
He probably also gave DeFazio AIDS. After watching his brother die from the disease in 1986, DeFazio tested HIV-positive. But almost seven years passed before he sought treatment. "I was always so stoned," he says now, "that the last thing I would have done was go to the hospital or to a doctor."

Finally, he sought help with his addictions at the state's Creedmoor Alcohol Treatment Center. Just one week later, he broke through his seven-year denial and told a doctor for the first time that he was HIV-positive.

Getting sober is often a prerequisite to seeking care. But if DeFazio were striving to break his cocaine and alcohol addictions today, he might well be denied help. The governor wants to cut back the state Office of Alcoholism and Substance Abuse Services by 12 per cent. That will force six of the state's 13 Alcoholism Treatment Centers to close, including Creedmoor, which is the only residential substance-abuse facility in Queens. In anticipation of the cuts, the state has ordered the six centers to turn away new clients. So now the 26-bed facility stands completely unused.

The Pataki administration argues that, even with its proposed cuts, New York will spend twice as much per capita on drug and alcohol programs as any other state. But that only makes the decision to ax Creedmoor and its sister programs all the more baffling, because they are highly efficient. They cost less per patient than private rehab programs, and they treat many more people. The centers have also received high quality-of-care ratings, with Creedmoor earning a special commendation.

Finally, advocates say that shrinking the state's large investment in substance abuse treatment is penny-wise but pound-



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social workers to assemble his "case" and verify his disability. The rejection forms don't give a reason; they just pronounce him fit to work.

Suspended in this limbo, Williams subsists on \$115 worth of food stamps

promised to make anyone with HIV qualify as unemployable. But they have yet to enact that provision, and Congress is not even considering such a provision for the food stamps bill. Denied the "unemployable" status, sick people with HIV

foolish. They point to studies which show that every dollar spent on drug and alcohol treatment saves taxpayers as much as \$7 in other costs, such as prosecuting the crimes untreated addicts commit.

DeFazio says that Creedmoor "saved my life" and "gave me back my family. The relationship I have with my niece totally blows me away. At one point I had stolen a VCR from her to get my drugs. Today, that kid gives me cards telling me I'm the best uncle of them all.

"I hear they're trying to cut these programs," says DeFazio. "Man, they don't know what they would be doing to people like me."

NADINE HUNTER

She lies in her bed, Bible on her stomach, commode within arm's reach. A few weeks ago, Nadine Hunter was released from the hospital. It was something of a miracle. She had developed diabetes, which is not uncommon among people with this disease, and her blood sugar rose so high that her doctors "didn't understand why I was not in a coma or dead."

It took three months in the hospital to pull her back from the brink. Fevers kept raging in her body, and her diarrhea was so severe that she had to be fed intravenously. She weighs 100 pounds now, 40 fewer than she did in full health. It shows in her face, where the skull protrudes too sharply under the skin, and in her activity, which is minimal. "Sometimes," she says, motioning toward the living room where the TV is on, "I get up and go to the couch."

For almost everything else—shopping, cooking, bathing, getting to the doctor—Hunter depends on her home health aide. In addition, a visiting nurse shows up every morning and evening to administer Hunter's insulin shots. Her case is not unusual. GMHC estimates that almost one-fifth of people with AIDS discharged from the hospital require home care. But Governor Pataki's Medicaid would slash such aid.

The cuts are complicated but boil down to this. If a patient needs *only* housekeeping—that is, if she is able to bathe and go to the bathroom but is too weak to, say, carry shopping bags or mop the floor—she will be out of luck. Under Pataki's proposal, New York Medicaid

will no longer pay for housekeeping unless, like Hunter, the patient is in such dire need of physical assistance that without it she would have to enter a nursing home. But even then, his proposal would effectively cap home care at five hours a day.

Hunter's attendant currently works with her 12 hours each day, so Hunter

wonders what she would have to skimp on if the governor's cuts pass: taking her to doctor appointments? Cooking? Shopping? Her attendant worries that Hunter, who, like many people with AIDS, suffers from mental confusion, might hurt herself while alone. Several times, Hunter has left the stove burning.

Without home care, says Hunter, "I

would be lost. I would really be lost."

IDELL GILLARD

She wanted her children back. But first Idell Gillard had to find decent housing.

It was grief and drugs that robbed



NADINE HUNTER
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Gillard of her children. After her husband died, she began "dipping and dabbing" in cocaine, which caused her to lose her job and then her apartment. Her three sons lived with relatives at first, then two went into boys homes. Gillard lived in abandoned buildings and parks. While homeless, she discovered she was HIV-positive.

She started treatment for her addiction, but could only afford to live in welfare hotels, notorious for being drug dens. "I was trying so hard to stay clean," she says, "but I couldn't in those hotels." Last year, she was finally placed in a Bronx one-bedroom apartment funded through a federal program called Housing Opportunities for People With AIDS. She's been able to stay clean, and one of her sons is living with her again. His basketball trophies stand proudly on the living room windowsill.

Gillard is hoping to find a bigger apartment for when her other two sons are released into her care, but she will be lucky to hold onto her current place. The HOPWA program pays for the homes of 1000 people in New York, and another 14,000 nationwide. But the House has voted to eliminate the program. Entirely. The Senate appears unlikely to restore the program, and with Governor Pataki and Mayor Giuliani paring their budgets, there is no fallback funding.

Losing HOPWA "would be devastating," says Idell, "because I would be homeless again." Being out on the streets would dash any hope of getting back her children; it would also shove her toward addiction and destroy her health. "When you're homeless, it's just impossible to take care of yourself. You have to duck in and out of bathrooms to wash." Noting that she's nearly completed a job-training program, she says, "Having my own door to open has opened a lot of other doors for me. If it was closed, that would close all the others, too."

LOUISE AND KRISTEN RIVERA

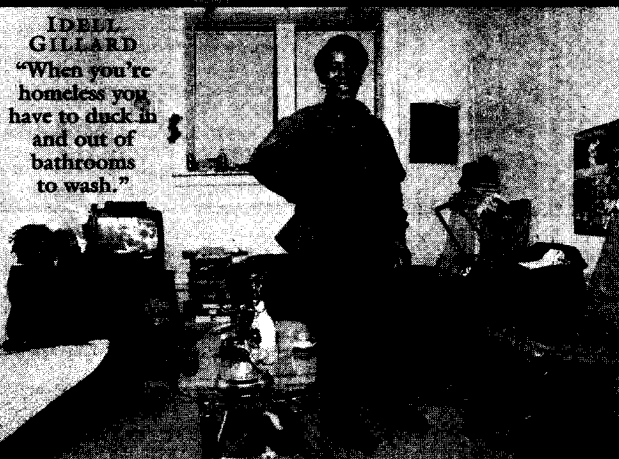
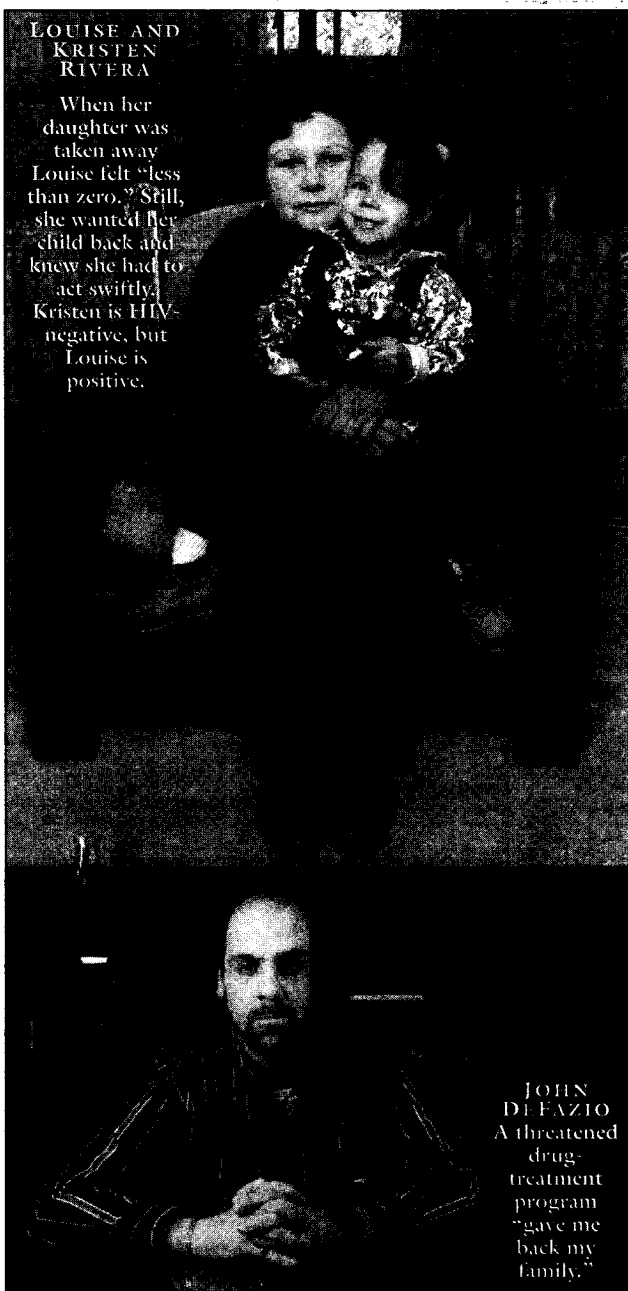
The day after Kristen turned one, five police officers and two social workers came to her home and took her away. Her mother, Louise Rivera, had fallen back into addiction. It wasn't the first time Rivera's habit hurt her child. She had passed cocaine through the womb, and Kristen spent the first days of her life in withdrawal. While most mothers can't stop gazing at their newborns, Louise "didn't want to face her. I thought the baby was going to say, 'Why did you do that to me?'" When Kristen was taken away, she felt the same "less than zero" shame, as if she had become "a monster." Still, she wanted her child back and knew she had to act swiftly. Kristen is HIV-negative, but Louise is positive.

Women are the fastest growing HIV population, and most of them are either IV drug users or sexual partners of men who are addicts. When they bear children—and many of them do—they are often unprepared for parenthood. Getting clean is the first step; developing parenting skills is another.

Rivera was given both by the city's Family Rehabilitation Program. The initiative is new—it was created to mend families torn apart by crack—but an assessment by a prestigious research insti-

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tute concluded that FRP has done "a remarkable job" in preventing children from being sent into foster care. That has spared the city "a heavy cost, not only in dollars but also in the toll drug abuse takes on young lives," says the assessment report. (Indeed, a City Council report estimates that placing children in foster care is six times more expensive than preserving the family through programs like FRP.) Such success is more dramatic given the program's clientele: poor single mothers with multiple addictions, most of whom lack a high school diploma. But the Giuliani administration has cut the FRP budget, terminating more than a third of its contracts.

One of the programs axed was Louise's. It helped her get clean, which she has been for almost a year and a half now. And, she says, the program taught her to "blend" with Kristen, a rambunctious, inquisitive three-year-old. Counselors asked Rivera to remember how she acted when she was a child. That brought back memories of how she was punished by being forced to kneel for an hour on rock salt. But it also helped her to have patience with Kristen and with herself. "I talk to myself a lot," she laughs.

Louise turns serious when asked what would have happened if it weren't for FRP. "I would be dead," she says.

All the cuts, and the suffering they would cause, raise a question: How do the Republicans expect these people to survive?

A clue slipped out last month, at a little noticed legislative hearing. Buffalo Assembly member Arthur Eve asked the new commissioner of social services, Mary Glass, about the proposed 90-day limit for employable welfare recipients. What would happen to such people if they couldn't find a job?

"I believe that they will find jobs working off the books," answered Glass.

Eve asked whether the commissioner was suggesting that these people would sell drugs.

"Some of them are selling drugs now," she replied.

Glass was talking about welfare recipients in general. But people with AIDS are among those the Republicans are forcing—with chilling premeditation—into drug dealing and prostitution. That couldn't be more dangerous, because shooting up and selling sex are vectors of HIV transmission. To force people with AIDS to enter the underground economy will, in addition to everything else, expand the epidemic.

Research assistance: Paul Scott